

Editorial

Introduction: Patient organization movements and new metamorphoses in patienthood

Abstract

In this introduction, we examine health activism as one expression of an emergent ‘politics of vitality’ or flurry of activity around health matters that includes: advances in technoscientific medicine, healthcare restructurings, and a re-thinking of science-society contracts. In querying politicized mobilizations around ‘health matters and the mattering of health,’ we provocatively entitle our discussion ‘patient organization movements’. This marks an invitation to interrogate (in reverse order) each term along the way, pausing in our concluding discussion to turn our attentions to the patient. The figure of the patient is thematized as an historical inscription and a formidable dimension of personhood under modernity/late modernity. Moreover, we argue that conventional categorizations of the patient are undergoing accelerated processes of change at the present time. We characterize three transformational trends: moves to author and authorize patienthood, mutiny from patienthood, and mutations in the category of the patient. Such metamorphoses in patienthood represent both reflections and repercussions—at once consequences and catalysts—of the proposed politics of vitality. We explore the pluralization of the patient’s persona via a closer look at the 11 empirical studies of health activism that comprise this collection.

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The politics of vitality

“Of all the pressing political issues of our day arguably none are more prevalent or insistent than are those regarding *health matters and the mattering of health*. Arguably none ring more with debate concerning rights versus responsibilities; arguably none have greater ramifications on the linkages between citizens and governance. There is at present a great flurry of activity ricocheting around health matters, an activity characterizing what we might describe as an emergent *politics of vitality*”. The politics of vitality is a broad label intended to capture both pro-active and reactive contests over health, writ large: from preventive to curative to palliative to normative to simulative to transformative to alternative projects and agendas. While several complex historical factors inform these contests, we emphasize four dominant spheres, or vectors, of influence: (1) revolutionary feats in technoscientific engineering, (2) restructurings of healthcare systems across industrialized nations, (3) a revised

‘contract’ between science and the public stemming from a crisis of confidence in science, and—last but not least for our purposes here—(4) an upsurge in the articulation and diversification of health activisms. Among the myriad and wide-ranging effects of the politics of vitality, we suggest, are the challenges posed to conventional ways of mediating and managing pathologies and bodies, identities and moralities, subjectivities and agencies. In this special issue we take an in-depth look at 11 empirical cases of health-spurred activism, based on a workshop on the topic co-organized by Kyra Landzelius and Joseph Dumit. We consider these cases of activism to be representations of the politics of vitality playing out via personal and collective engagements, with ripple effects along relations of power spanning from the transnational to the local (and vice versa), and from macro-political articulations to what Foucault has called the “micro-physics of power” (Foucault, 1994). The cases here illustrate a range of ‘causes’ of activism framed by association to health and/or disease, specifically: AIDS,

mental illness, muscular dystrophy, chronic fatigue syndrome and multiple chemical sensitivity, breast cancer, contraceptive technologies, miscarriage and stillbirth, anti-immunization sentiments, anti-aging advocacy, the question of voluntary euthanasia, and techno-scientific invention in the care of preterm babies. In querying these instances of health activism as both reflections and repercussions—at once consequences and catalysts—of a proposed politics of vitality, we take the opportunity to examine their ramifications for the *category of the patient* and *patienthood*.

There is every indication—from public sphere events, news media and policy initiatives, changes in the doing and reporting of science, clinical encounters or cruising the internet, the involvements of family and friends, and perhaps our own practices and attitudes—to suggest that varieties of activism, politically charged and mobilized specifically with regard to health issues, are on the rise. This is a trend that has not gone unnoticed by social scientists. Indeed, one telltale sign of the arrival of a new terrain for theoretical interrogation is the current terminological juggling and proliferation, the grasping for conceptual control to get our collective minds around an emergent phenomenon. Apropos this question of terms, for our part we have here entitled this collection ‘patient organization movements’: a label that clearly calls attention to the figure of the patient, the phenomenon of organization, and the dynamics of movements. This label is intended to be triply provocative, our intention is that each term be apprehended as an opportunity to probe, prod and prompt our analyses of politicized mobilizations in the name of health. We begin by interrogating the caliber of the descriptor “movement”, and work our way backwards through a query into “organization” and finally an examination of “the patient”. We linger at length on the latter, as it is the principle concern in our discussion here and ultimately the primary object/subject of trends driving a politics of vitality.

Tasking social movement theory

As a growing field of scholarship attests, there is at present a re-thinking and re-working of social movement theorization in efforts to better grasp the cross-cutting and muddled dynamics common to emergent health-related activism. Much of this theorizing has focused on the instrumental-collaborative bonds linking grassroots participants, state institutions, industry workers, NGO workers, medical practitioners, media representatives, scientific experts, lobbying groups of various kinds, and even the public at-large. Two predominant preoccupations might be said to surface from researchers’ investigations, ruminations and new propositions. One marks a concern with how various actors are

(multiply) positioned, and traces the nature and traffic of their transactions. This thrust could be characterized by its focus on the geometries of composition and connectivity. In grappling with structures that tend to pattern in a rhizomatic fashion, Wolfson (2001) introduces the notion of “interpenetrated social movements”, Klawiter (2003) discusses “hybridized social formations”, Ganchoff (2004) emphasizes “multiple sites for citizen participation”, Frickel (2004) discusses collective action framing and “interdisciplines”, Stearns and Almeida (2004) underscore “coalitions”, Schneirov and Geczik (2002) talk about “dual movements” and McCormick, Brown, and Zavestoski (2003) talk about “boundary movements”. The second preoccupation arising from researchers’ musings and phrasings alights on questions of how power is distributed along paths of conflict and mediation, and the resulting implications for resolution and its forms. This thrust might be gathered under reference to algorithms of power arrangements. Along these lines, Crossley (1999) envisions “fields of contention”, Mercer (2002) proposes “vertical integration and hyper-experts”, Rabeharisoa (2005) emphasizes “mediational” roles, Hess (2004) highlights “epistemic politics”, and Duyvendak and Nederland (2004) underscore the instrumental tensions between narrow and broad presentations of “civic identity”. As the twin pillars of social movement theorizing, it goes without saying that the two theoretical bends—the dual considerations of structure and power—are contingent and represent systematic and (interestingly enough) convergent attempts to grasp just what is particular about collective action mobilized around health. Epstein’s now classic work on the topic directed the critical edge of analysis to the epistemological target, namely health activism’s penchant to challenge the construction of knowledge and expertise (as keenly exemplified by ACT-UP’s fight against biomedical hegemony in the management of AIDS, see Epstein, 1995 and 1996). More recently Brown, Zavestoski, McCormick, Mayer, and Morello-Frosch (2004) have aimed to typologize health movements, based largely on how a given movement’s objections might be said to “interface” with biomedical productions (whether championing for greater inclusivity or resource parity, or challenging some aspect(s) of biomedicine’s overall machinery, including its paradigms and technologies). Clearly a number of scholars find social movement theory fruitful yet, as presently construed, inadequate to the task of handling the prolific kinds of activism presently underway in relation to health matters (see also in this context: Allsop, Jones, & Baggott, 2004; Brown & Zavestoski, 2004; Cartwright, 2000; Clarke, Shim, Mamo, Fosket, & Fishman, 2003; Joffe, Weitz, & Stacey, 2004; McCally, 2002; McCormick, Brody, Brown, & Polk, 2004; Morgan, 2001; Potts, 2004).

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